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## Abstract

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**PI Title:**

**Project Title:** ETHICS AND PARENT COLLABORATION IN NICU END OF LIFE CARE

**Abstract:** *The long-term objective of this KO1 is to further develop the investigator's ethics theoretical orientation and research skills to improve end-of-life care for extremely premature infants and their families. At present, very little is known about what represents optimal end-of-life care within the neonatal intensive care unit (NICU). The proposed study will examine current end-of-life care practices and will use a parent- professional collaborative process to define exemplary end-of-life care. The ethical concerns examined in this study include the imperative of parental involvement in the health care of their infants, the obligation to provide compassionate and humane care, and the consideration of burden of treatment for extremely premature infants in the NICU. Research training activities will be conducted over a 4-year period and are centered around objectives to: (1) document current NICU end-of-life care practices through a national survey; (2) determine parental preferences regarding end-of-life care for their extremely premature infants; (3) establish parent-professional collaborative groups at two research site NICUs to develop and implement end-of-life care guidelines; and (4) evaluate changes in practice following guideline implementation. This project design incorporates quantitative and qualitative study of clinical ethical issues and the development of a model of parent-professional collaboration and ethics theory application in neonatal end-of-life care. The mentor will supervise the applicant throughout all phases of the proposed study.*

**Thesaurus Terms:**

*ethics, neonatal intensive care, parent, patient care personnel relations, premature infant human, terminal patient care*

*behavioral /social science research tag, clinical research, human subject*

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